## The Millennium Series in Women's Health

## Women's Health Centers and Minority Women: Addressing Barriers to Care. The National Centers of Excellence in Women's Health

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#### **ABSTRACT**

New models of care delivery have been developed to better coordinate and integrate health-care for women. In the United States, one of the challenges is to incorporate the needs of racial and ethnic minority populations into these newer care paradigms. This paper begins with a brief historical review of the experience of racial and ethnic minorities in the American healthcare system to provide a context for discussing barriers and limitations of more traditional models of women's healthcare. Specific approaches used by National Centers of Excellence in Women's Health are presented as examples of strategies that may be implemented by other communities to address these barriers.

## INTRODUCTION

Over the last 20 years, new models of healthcare delivery for women have emerged in the United States. Coordinated and integrated care systems are replacing the fragmented care of past decades. Unfortunately, persistent racial disparities in health access, quality, and status provide continuing evidence that the U.S. healthcare system is differentially responsive to the needs of

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its diverse population. One of the challenges to newer models of women's healthcare is to create systems that are appropriate and responsive to the racially and ethnically diverse American female population.

In 1996, the Department of Health and Human Services (DHHS) established National Centers of Excellence in Women's Health (CoE) to serve as models of more comprehensive approaches to women's health. Efforts to investigate genderbased differences in symptom and disease expression, educate and train future providers, better fund research specifically addressing health problems of women, advance women as leaders in academic medicine, and identify and modify ineffective practices and policies are integral components of CoEs. Early results suggest that CoEs serve a more diverse female population than more traditional models of care. Thus, they provide a conceptual framework for addressing barriers to care for minority women.

The purpose of this paper is twofold: to describe barriers to effective healthcare for minority women, including limitations of current healthcare delivery models, and to provide examples of strategies being implemented by COEs to address these barriers.

#### HISTORICAL REVIEW

The fact that race is a powerful determinant of health continues to be a major blight on the American healthcare landscape. From the days of medical experimentation on slaves<sup>1</sup> to the Hill-Burton Act of 1946, which perpetuated the "separate but equal" principle of segregated health care,<sup>2</sup> to the U.S. Public Health Service's study of syphilis conducted in Tuskegee Alabama,3-5 the history of medical care for many minority groups in the United States is one of exploitation, segregation, and discrimination. Black, Latina, and American Indian women have faced unique circumstances of bias, discrimination, and exploitation (sterilization abuse, for example<sup>6</sup>). Healthcare practices of previous decades mirrored societal belief in theories of genetic inferiority and biological dissimilarity of nonwhite racial groups. Although such theories have been disproved and largely abandoned, underlying prejudicial attitudes and behaviors have proved much more difficult to alter.

Historically, a woman's access to healthcare

was based on her maternal status. As early as the 1800s, policies and laws prohibiting contraception and abortion were enacted, in part, to preserve a woman's reproductive status and maternal role.<sup>7</sup> Even after public health experts became aware of the negative health consequences of pregnancies that were too frequent and too numerous, health and welfare policy was based on reproductive status. However, policies began to change during the women's health movement of the 1960s and 1970s, as women sought to gain control over their own reproductive status and define the type of healthcare they desired.

This organ-based approach to women's health also formed the basis of federally funded health access programs. The largest program tied to Medicaid eligibility, Aid to Families with Dependent Children (AFDC), targeted reproductive age women and their children.<sup>8</sup> Other federal programs, such as Title X funding for family planning and the Women, Infants and Children (WIC) supplemental food and nutrition program, were justified as a means of protecting the health of reproductive age women and their children. Thus in the United States, women's healthcare has been largely synonymous with reproductive health care.

# HEALTHCARE DELIVERY IN THE 20<sup>TH</sup> CENTURY

Superimposition of specialized medicine on the reproduction-based healthcare system for women further extended the organ-based approach, resulting in a delivery system that is poorly coordinated across providers. This system of care does not fully address the needs of any group of women and, specifically, magnifies the barriers to care for minority women, who may lack both the resources and knowledge necessary to navigate the system successfully.

A number of new models of healthcare have attempted to address the lack of coordination in women's healthcare. These include reproductive health centers, primary care centers, and specialty services centers. Reproductive healthcare centers developed after the nationwide legalization of contraception and abortion. These centers rely in part on government support (Title X funds) and serve women who lack the resources necessary to access reproductive health services in other settings or who are unable legally to obtain con-

traceptive and abortion services elsewhere.<sup>10</sup> (Title X funds cannot be used for abortion services. Centers that provide both contraceptive services and abortion services must separate them in order to qualify for Title X funding.) Thus, while providing services to minority women, by design they do so in isolation from other aspects of health care, further fragmenting care to minority populations who may be more dependent on publicly supported services than are white women.

Primary care and specialty centers began in response to the growing interest in women's health. The centers began systematically to address the gaps in healthcare services for women and the lack of coordination in care, developing alternatives to traditional paternalistic approaches and reducing the number of providers women needed to see to receive comprehensive primary care services. 11 Unfortunately, these efforts took place in a climate of limited financial compensation, thus creating a need for institutional or other financial support. As the demand for women's health services increased, hospitals and clinics began providing products attractive to middle-class and affluent women (e.g., alternative health therapies and personal appearance and wellness products, such as cosmetic surgery, corrective eye surgery, and dermatological services) as a means of generating revenue and disposable income to cover increasing costs. 12 Consequently, many women's health clinics are subsidized by these alternative services in order to ensure a more stable revenue stream.

Services offered by specialty centers often focus on conditions or procedures with predictable downstream revenue (e.g., breast health services with mammography and biopsies, and menopausal evaluation with bone densitometry). Such centers are more likely to be situated in or are readily accessible to communities where women have the necessary resources to afford these services. Thus, new models of comprehensive care to women have targeted middle-class, primarily insured, Caucasian women.

## BARRIERS IN HEALTHCARE DELIVERY TO MINORITY WOMEN

Many minority women face numerous barriers that limit access to comprehensive care, including policy, institutional, and interpersonal barriers. Policy barriers limit access to healthcare from the perspective of distribution and management. Cost reimbursement strategies are foremost among policy barriers. Institutional barriers tend to create and maintain care delivery environments that are or are perceived to be insensitive, unfriendly, or even hostile to minorities. Interpersonal barriers can be viewed as those that limit a person's ability to optimally use or provide healthcare services.

Although these barriers are not specific to minority women, they are particularly burdensome in these populations. This is due in part to the absence of minority women on policy decision-making boards and to the inadequate supply of minority physicians in general and minority female physicians in particular. Some of the more salient barriers are presented in the following sections.

## Policy barriers

As is evident from the previous discussion, provision of one-stop shopping is clearly a goal of newer care models for women. However, the current fiscal realities of developing new models of healthcare services for women have a direct and negative influence on the needs of minority women. Academic and clinical sites seeking to provide comprehensive care for low-income, minority women often are not able to find sufficient resources to cover expenses and, therefore, have been unsuccessful in sustaining the effort. Because the downstream revenue provided by major illnesses is insufficient to offset primary care expenditures, there are insufficient funds either to subsidize primary care or coordinate primary care with specialty care. The disproportionate representation of minority women among the publicly insured, underinsured, and uninsured exacerbates this problem.

Clearly, cost remains a major policy barrier for the provision of comprehensive care to minority women even where models for care to insured women now exist. <sup>15</sup> Although there is considerable heterogeneity, a greater percentage of minority women, as compared with majority women, are either underinsured or uninsured and, therefore, cannot afford adequate healthcare. <sup>16</sup> Even those who are employed often hold lower-paying, semiskilled or unskilled positions and may not be insured through their employers. <sup>17</sup>

The recent emphasis on managed healthcare as a way to control costs has left minority women with several additional obstacles even when they have employer-based insurance coverage. Research suggests that reimbursement strategies for providers in managed care organizations affect resource use without compromising health outcomes.<sup>18</sup> However, health providers and other organizations concerned with providing care within a given monthly cap may perceive minority women to be at greater risk for poorer health than majority women and, thus, less desirable financially. African American, Hispanic, and uninsured patients are more likely to receive care from minority physicians, 19,20 who, unfortunately, may not be included in managed care plans, leaving minority women with even less choice than they have in nonmanaged care plans.

Other policy barriers can arise from well-meaning programs designed to address reimbursement disparities, potentially leading to further fragmentation of care. For example, the Centers for Disease Control and Prevention (CDC)funded, state-administered programs for breast and cervical cancer screening provide access to screening services by providing financial reimbursement to healthcare providers. However, there was no comparable provision for treatment or therapy should a malignancy or other problem be detected, leaving underinsured and uninsured women with continued access problems. Although the CDC now provides special Medicaid coverage to women diagnosed with cancer or in need of treatment, the omission of treatment options in the original program shows how categorical approaches to disease, or "legislation by anatomy," can reinforce fragmentation of care for minority and other disadvantaged women.

### Institutional barriers

Cultural discordance. One of the greatest barriers to healthcare for minority women is the under-recognition of the profound influence of culture on both the delivery and receipt of healthcare. Two concepts are important in this context: cultural sensitivity and cultural competence. Cultural sensitivity refers to an awareness of the diversity in values, beliefs, and lifestyles that exist among population groups within a society. Cultural competence reflects the ability to apply knowledge about cultural differences to the delivery of healthcare. A presupposition of cultural

competency is that no one and no system is culture free.<sup>21</sup> Thus, the general medical culture, the patient's culture, and the provider's culture all warrant attention.<sup>22</sup> That the practice of medicine in the United States has its own culture is suggested by the term "Western medicine," which reflects the underlying Eurocentric foundations.

Among cultural barriers, differences in spoken language present some of the greatest hurdles to both the delivery and receipt of appropriate healthcare. Whether the differences are in primary language (e.g., Spanish vs. English) or in jargon/terminology (e.g., hypertension vs. "high blood"), the inability to communicate effectively severely limits all aspects of the care process. Even healthcare professionals perceive significant improvements in the efficacy of care provided when skilled interpreters are available.<sup>23</sup> Unfortunately, most written documents and ancillary services are English-only, further complicating care delivery for non-English-speaking populations.

Other cultural differences can also lead to difficulty in scheduling appointments, miscommunication between providers and patients, misdiagnoses, and poor compliance and poor follow-up on the patient's part.<sup>17</sup> For example, care providers who are unfamiliar with *simpatia* (kindness), *personalismo* (formal friendliness), or *familismo* (familial loyalty) will not understand that certain actions are perceived as inappropriate and negative by Latino or Hispanic patients.<sup>24</sup>

Even though the literature is mixed, evidence indicates that minority patients not only seek out providers from the same racial or ethnic group but also tend to be more satisfied with the care received.<sup>25</sup> Several studies indicate that ethnic and racial minority patients report greater satisfaction and more complete preventive and medical care, rate their provider more highly, and rate their physician's decision-making styles as more participatory when their physician is from the same racial and ethnic group as they are.<sup>26,27</sup> These findings suggest that cultural incompetence in healthcare extends beyond simple differences in spoken language. Cultural competence is tied to quality of care and is a crosscutting issue affecting all service delivery systems and providers.

Education of health professionals. Issues relevant to the education of health professionals may per-

petuate problems in the current healthcare system for minority women. Such education remains largely focused on the biophysiological model of disease processes, with less attention given to social, cultural, and psychological dimensions of health. Many medical schools are still working to integrate women's health issues into the traditional template but have yet to incorporate the concepts of cultural diversity and population heterogeneity. Normative patient examples used remain predominantly male and usually Caucasian.

In addition, necessary interactions with social services, managed care organizations, and community-based health providers and facilities are not well integrated into current curricula. As a result, students may have limited understanding or appreciation of the wide range of personal beliefs and sociocultural realities that influence health and the experience of healthcare. Until these issues are addressed in medical and other professional education, efforts to create a culturally competent care delivery system and care provider will be limited.

Institutionalized racism. A key component of cultural competence involves acknowledging both the impact of racism on health and the existence of institutionalized racism within health-care. 28,29 "Institutionalized racism . . . can be seen or detected in processes, attitudes and behaviors which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantage minority ethnic people." Institutionalized racism produces discriminatory effects on health through public policy, the physical environment, social and medical services, and preventive health policy. 30,31 It ranges from the subtle (e.g., the well-documented racial differential in the use of medical technology) to the overt.

One of the more subtle indicators of institutionalized racism is the lack of diversity in professional and upper administrative ranks. <sup>13,32</sup> The underrepresentation of minorities in general and minority females in particular in upper level administrative positions, as members of house staff, and in other positions of leadership within the healthcare system makes it unlikely that the unique needs of these populations will be given high priority. It is even less likely that institutional barriers to access will be identified, acknowledged, and corrected.

Interpersonal barriers

Interpersonal barriers also may limit a minority woman's ability to access and successfully navigate the healthcare system. Such factors as limited knowledge and education, high cost, inhospitable or inaccessible services, lack of insurance, lack of transportation, inconvenient locations, and refusals by clinics or physicians create nearly insurmountable obstacles to health care.<sup>33</sup>

Although much of the focus on improving the health status of minority populations is directed toward patient attributes, the experiences, values, attitudes, and biases of providers also have important effects on healthcare from both a care delivery and policy setting perspective. A recent study conducted by the Lewin Group for the Columbus Medical Association Foundation identified interesting differences between care providers and recipients.<sup>34</sup> In this study, healthcare professionals identified transportation and difficulties understanding minority patients as important problems. In contrast, care recipients identified negative attitudes and practices of healthcare professionals toward minority populations as a major area of concern. This discordance underscores the need to increase ethnocultural diversity and cultural competence among providers in order to identify and overcome barriers to care for minority women.

## TOWARD A MORE INCLUSIVE MODEL: MINORITY WOMEN AND WOMEN'S HEALTHCARE

An ideal model of women's healthcare that is inclusive of minority women is necessarily different from models that have been designed and adapted without consideration of this population. However, even a model of care with a specific focus on minority women would not meet their needs if not developed within the context of the larger social environment. 35,36 Care for and health status among women of color will not improve without simultaneous efforts to reverse inequities in economic status, educational attainment, community safety, environmental justice, housing, and other factors that negatively impact health. Within the larger societal context, an ideal model of care for women of color must take into account providers of care, content and process of care, and the healthcare system in which the model operates.

### **Providers**

Ideally, care providers should reflect the diversity of the population served. Although impractical at present, a diverse provider population should be a long-range goal of educational institutions and healthcare organizations. As a short-term goal, however, current providers must be encouraged or required to acquire the knowledge, attitudes, and skills necessary to provide more culturally competent care to minority women.<sup>37</sup> They must also be encouraged to actively seek new information about the needs and health concerns of minority women and to advocate for them in the larger healthcare system. In the more inclusive women's health model, providers will be members of multidisciplinary teams of physicians, nurses, nurse midwives, mental health providers, social workers, outreach workers, health educators, and case managers who work together to address the complicated social and medical needs of minority women.

## Content and process of care

Although much has been written about the ideal content of care for women, 38,39 little attention has been given to the concerns of minority women. Because minority women often have a higher burden of illness, poorer health outcomes, and a higher prevalence of risk factors for chronic disease than other women, a more inclusive model of care not only must be comprehensive but also must provide for continuity of care across providers and specialties. The breadth of care must cross the life span of women from adolescence to older age, addressing prevention, primary care, care of chronic disease, reproductive health (including all legal services related to reproductive care), complex psychosocial issues, and mental health.36

Ongoing comprehensive risk assessment, community outreach, case management (not care or resource management), interpreter services, and health education should also be integral components of the more inclusive model. Outreach activities facilitate access for women who traditionally are difficult to engage in care or who drop out of care. Case managers should serve as bridges between minority women and healthcare institutions and as links to appropriate community resources. Interpreter services ensure more appropriate care for those with limited English proficiency.

This model requires reallocation of resources

to get women into the system and connect them to ongoing care. Strategies such as providing transportation, locating facilities in nontraditional settings (e.g., neighborhood centers, churches), and extending operating hours to acknowledge the multiple roles of women as parents, caregivers, and members of the paid workforce should be considered. These strategies are especially relevant for minority women who are more likely to be single heads of households.

An important aspect of the care process is ongoing evaluation. Quality of care should be an important outcome measure for the more inclusive model. Methods to document and track access and health status outcomes in addition to measures that reflect minority women's concepts of health and wellness must be included in the evaluation process.

## Institutional roles

Institutions that sponsor women's healthcare models and practices must be committed to key concepts of diversity and social justice. The institutions must have minority women in key leadership and policymaking positions, staff who demonstrate cultural competence and sensitivity, strategies to solicit input from the communities being served, and mechanisms to incorporate the communities' recommendations into the day-today operations of the institution. Private and public institutions must be willing to partner with public health efforts to ensure that resources are allocated fairly and that minority women experience a seamless continuum of care between the private and public sector providers.35 Such partnerships will also be uniquely positioned to monitor the impact of new policies and procedures on the health of minority women and inform government bodies of increasing barriers to care. The recent passage of the Personal Responsibility Act is an example of how private and public institutions must partner to ensure that women do not inadvertently lose Medicaid coverage and that economic hardship does not negatively affect an already vulnerable population's ability to engage in care.

# EXAMPLES FROM WOMEN'S HEALTH COEs

Located in leading academic health centers across the United States and Puerto Rico, the

TABLE 1. OUTREACH PROGRAMS DEVELOPED BY COES

CoE	Program title	Purpose/audience
Magee Women's Hospital	Health Advocacy for New Americans (HANA)	Breast cancer awareness; breast health for Russians
	WomanCare	Health education for African Americans
Harvard Medical School	Women Enjoying Longer Lives (WELL)	Preventive healthcare for minority women
University of Illinois	Women Improving Their Health in Neighborhoods: The The Roseland Project	Physical activity promotion for African American women
University of Michigan	Programs for Multicultural Health (PMCH)	Health education for African Americans, Latinas, Asians
University of Puerto Rico	Conference Hall on Wheels	Health promotion for Hispanic women
University of Wisconsin Madison	Health Outreach to Wisconsin Adolescents (HOWA)	Risk reduction for adolescent girls from Indian nations
Wake Forest University	Health at the Well	Modular health education series for African Americans
	Living Water Family Resource Center	Prenatal and breast screening clinic for African and Hispanic Americans

CoEs are developing new models for women's healthcare that are setting standards beyond what is traditionally offered at hospital-sponsored women's clinical health centers. The infrastructure of COEs was designed to facilitate the integration of critical components of women's health. Core program areas include education, research, outreach, leadership, and clinical services. This infrastructure not only provides an effective framework for addressing barriers to care for minority women but also allows close coordination among critical components, such as education and clinical services.

A comparison of the populations served by

COEs with those served by other women's health models indicates that COEs serve a greater proportion of women from underrepresented minority groups. 40 Thus, CoEs provide examples of women's health models that target a broader cross-section of women. Examples of strategies being implemented by COEs to address barriers to care for minority women are described in the following sections.

## Policy barriers

As discussed earlier, cost is a major barrier for minority women. To address this issue, the

TABLE 2. EDUCATIONAL PROGRAMS AND RESOURCES DEVELOPED BY COES

CoE	Course/seminar title	Audience
Undergraduate, Graduate, Faculty, Staff		
Boston University	Addressing barriers to care	Boston University's 4000+ employees
University of Michigan	Diversity training workshop	Staff; community volunteers
University of Wisconsin- Madison	Health promotion and disease prevention for diverse communities	Graduate level nursing students
Yale University	Doctor-patient encounter	First and second year medical students
Consumer		
University of Maryland	Cancer awareness, prevention and control for African Americans	African American women
University of Pennsylvania	Breaking the Silence Health Tip Card Project	African American women
Wake Forest University	A health guide to improve the health of Hispanic women	Hispanic women

Boston University (BU) CoE successfully networked with the Boston Medical Center, which serves as the safety net institution for the City of Boston. As a result of this linkage, the BU CoE is able to use resources from the uncompensated care pool provided by the State of Massachusetts, interpreter services in multiple languages, outreach programs to specific communities, and a network of referral services that accept patients regardless of ability to pay. Other CoEs have also established alliances and networks to promote ongoing dialogue and collaboration with ethnoculturally diverse communities.

### Institutional barriers

All CoEs, via their core program areas, have implemented strategies to address problems related to cultural discordance, medical education, and institutionalized racism. These include outreach programs (Table 1), translation of materials into several languages, including Spanish, Chinese, Russian, and Vietnamese, and community alliances and partnerships.

These outreach programs deliver state-of-theart information and services directly to minority communities. For example, the Wake Forest University CoE's Living Water Family Resource Center is housed in a community church within a triethnic, low-income community. The University of Puerto Rico's Conference Hall on Wheels is a mobile unit that tours the island promoting widespread awareness of the healthcare needs of women across the life span.

Education is a necessary component of any strategy to minimize institutional barriers to healthcare for minority women. CoEs have developed and conducted undergraduate, graduate, faculty, and staff classes, workshops, and seminars to educate the care community on issues from diversity to cross-cultural health beliefs (Table 2). In addition, many CoEs have developed or are in the process of preparing other consumer health resources, including websites, videotapes, fact sheets, brochures, and newsletters, to assist in educating patients and the public. Leadership Development Programs have been implemented by CoEs to address the lack of institutional diversity on faculties and in higher administrative positions. These development programs for women and minorities include mentoring for faculty and students, collaborative efforts to recruit, retain, and promote women and minorities, and leadership and advocacy skills training.

#### **SUMMARY**

The changes that are taking place in women's healthcare delivery have been long needed. As care paradigms change, however, actions must be taken to prevent or at least minimize the recurrence of factors responsible for the differential care rendered to minority populations. The CoEs were established to integrate state-of-the-art clinical care for women, ensure equitable access to healthcare across socioeconomic and ethnic backgrounds, and implement procedures to recruit more diverse women for research, work for the advancement of women in medicine, and provide education on women's health issues to healthcare providers. Early results suggest that the CoE serve a more diverse female population than more traditional models of care. As such, they provide a conceptual framework for addressing barriers to care for minority women and can serve as sites to evaluate the effectiveness of alternative models of care.

Of the many barriers encountered by minority women, those related to healthcare costs and cultural discordance are most prominent. Alliances and partnerships, such as those established between CoEs and minority community organizations, allow the dialogue necessary to identify and recommend solutions for barriers to care. These alliances can also provide for more efficient coordination of available services. Outreach programs provide state-of-the-art information and clinical services directly to communities and thereby increase access. Educational programs for students, staff, faculty, and consumers serve multiple functions and can be a means of promoting a more culturally appropriate care environment. Leadership programs provide tangible strategies for increasing ethnocultural diversity among care providers. Finally, with programs in education, research, leadership, and clinical services, the CoE model permits coordination of a more comprehensive care paradigm for minority women.

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